

Inquire 2 Inspire: Parenting without Pigment

By Kathi Garza, *Albinism InSight* Staff Writer



For as long as I can remember, I have wanted to be a mother. I never really questioned how I would parent without pigment. It never occurred to me that my visual impairment might get in the way of the demands of motherhood. I attribute this not to overconfidence but to my experiences in life. I grew up with a large extended family where a new baby was always entering the world. I began babysitting at a very early age, and I worked in child care for a few years. I had a lot of time and opportunities to develop strategies which helped me care for my charges despite my visual impairment. My son was born in December, and it occurred to me that others in the community might not have had the same opportunities to practice which led me to inquire:



What strategies have you developed to help you adapt to parenting without pigment?

Although I wasn't overly concerned with how I would manage my newborn once he got here, I began to worry about how I would access the excitement of pregnancy. I knew that I would

struggle to see ultrasounds, the gender of the baby and the many features expectant parents strain to make out on that small monitor in the doctor's office. Speaking of the office, I stressed over the excessive light and noise that would make me feel anxious during childbirth. Before allowing myself to become irrational, I decided to speak to the doctor.

I took my monocular to all my appointments, and I asked to situate myself to ensure I could see the monitor before the ultrasound began. After a quick explanation of my visual impairment, the techs often checked to make sure I saw what they were discussing with my husband. A little self-advocacy went a long way in helping me feel connected to what was going on. That success gave me confidence to speak to the doctor about the conditions in the delivery room. The doctor assured me that they would keep the room as dim as possible without compromising their ability to care for the baby and me. I was also encouraged to wear a hat and sunglasses. This made my experience very positive and less stressful.

Beyond pregnancy, let's see what some of our friends in the albinism community said about parenting without pigment.

Although I'm still learning, the past three years have taught me a lot about motherhood and about myself. As with many changes in life, the thought of being a parent initially caused me some fear and self-doubt because of my vision. I questioned how I'd be able to do those daily tasks and independently take care of another living person. Shortly after Phoebe was born, I realized two things. First, all new parents are terrified and clueless, so my fears actually had very little to do with my vision. Secondly, being a mom comes naturally with time – regardless of one's visual capabilities.

I learned how to work around little challenges, like grooming tiny, squirmy, newborn baby fingernails by filing them down with a nail file instead of using clippers. Later, I learned how to identify my toddler on the playground amidst a sea of identical, bouncing kids. It turns out that those obnoxious light-up toddler shoes are a godsend for low vision mamas! From an early age, I took my daughter on public transportation out of necessity. Today she's the most well-behaved, savvy three-year-old kid on the bus. We have even found simple ways to accommodate story time so I have a chance to read the words, and Phoebe has a chance to see the pictures. Kelsey T. – Chicago, IL



Phoebe and Kelsey T.



Lee L. and her family

I used my monocular when I needed to pick my children up from the playground after school. I stood at the edge of the playground, found the equipment, and used my monocular to locate each child. This allowed me to walk directly to my children rather than walking around and looking. Luckily, no one ever reported me for stalking! My monocular also came in handy while watching them perform in plays and concerts. Joni V. – Cudahy, WI

The biggest challenge for me is keeping track of my kids. When my son got a new ski helmet, it was black. At my request and with his permission, my daughter personalized it with neon orange and yellow duct tape. Now when we're skiing, I can pick him out of a crowd of helmets, and he can find his helmet in a pile of ski gear! I also rely on call and response. My kids learned at a young age to answer when I call them. If they do, they can maintain their freedom. If they don't, when I do find them, they are glued to my side for the duration of our journey, and I can assure you that their mom rarely goes where they want to go. Lastly, when they were little, I would say, "Stay where you can see me." That empowered them to work within their limitations. Lee L. – Loudon, NH

There is no shame in using a leash backpack when out and about with your toddler. It gives her a sense of freedom to explore while giving you a sense of security. I also think we need to believe in ourselves and understand that we may need to do

things differently than other people. There are many different theories on parenting and everyone has an opinion on what you should do – even if you aren't visually impaired. We must not let family, other parents, books or society bring us down when making decisions for what we think is right for ourselves and for our children. I remember feeling so judged the first time I wanted to take my six month old on the bus. However, after I did it, I felt empowered and confident! Marleena B. – Anaheim, CA

I reduced the bright light in my home to help me function better. I bought larger print books, or I read to my kids under a brighter light. Cindy B. – Madison, AL

One workaround that pops to mind is checking a sleeping baby. I couldn't see the rise and fall of my son's chest, so I gently placed a hand on his back. Another important strategy is to let your child know early on that you can't see as well as he can. Young kids have a great ability to understand and accept things. One of the most touching memories I have occurred when my son was about five years old. One day, he noticed I was having trouble reading something. He got a magnifier out of the drawer where I kept it, and asked if I needed it. Mike M. – Chicago, IL

In Australia, school children all wear school uniforms and look the same in the sea of kids. I told my kids they have to find ME in the afternoon or they had to sleep at school all night! I trained them to do this in all situations to be safe. They do it without thinking now. They also automatically read subtitles in movies to me. Annette F. – Dubbo, Australia

I have never been one to discuss my albinism, not even with my daughter. However, an interesting phase of our relationship occurred when she attended her first NOAH event. At

NOAH Family Camp, my young teenager had the opportunity to interact with teens with albinism. They talked at night in their bunks. It was the first time she really heard about and understood albinism and some of the challenges it brings. In many ways, I think she internalized the information better when it came from her peers. Robert G. – Boston MA

The most important insight into parenting was that I could do it. I learned to be my own best advocate. I always told my kids that there was nothing they could not do, and we offered lessons and various experiences without imposing expectations. Richard, B. –Tucson, AZ

Those are some great strategies. One tip became a theme in several responses I received. "Ask your child to help you see." Here are some situations where children were empowered to accommodate parents without pigment.

While riding the bus, my daughter and I played a game of "who could see the bus first." With regard to toys, I would say, "If you value your toys, pick them up. Otherwise, I may step on something and accidentally break it." When we traveled, my daughter knew she was my second set of eyes. I think that taught her compassion, and she often educated her peers about having a parent with albinism. Natalie D. – San Francisco, CA



I ask my children to read things like street signs and addresses for me. Before they were able to help me, I made a lot of U-turns! Eve S. – Virginia Beach, VA

It was exciting when our oldest child could drive because it was easier for me to get around when my husband was working. My kids would often joke about who was next to give mom a ride because they knew they'd have my stories to listen to in the car. Linnea H. – Pasco, WA

One final, uplifting thought!

There is so much you can give to your children besides albinism. You can give them yourself and your family. A family is made up of all the wonderful things that go into it, tradition, love, faith and anything else you have. Virginia C. – Washington, D.C.

It sounds like our friends in the albinism community have this parenting thing under control! I learned a lot, but above all, I agree

with Kelsey. In my experience of speaking to my pigmented friends, WE ALL worry about caring for another human being. We all want to do our best and must find ways to overcome a variety of obstacles in parenting.

Now we need YOU to Inquire to Inspire. Send your questions with regard to issues faced by individuals in the albinism community to **i2i@albinism.org**.